Paediatric ART Delivery: Challenges and Solutions to Increasing Access

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Presentation Outline

- Study Purpose
- Methodology
- The Framework of Analysis
- Caregivers
- Service providers
- Summary Note

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Study Purpose

- To provide information re: current practices and perceptions relating to the treatment of children with HIV/AIDS with a view to making recommendations regarding expansion of ARV access to children

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Data and Methods

- Rapid situational analysis study conducted between 11 April to 21 June 2005
- A convenience sample of 16 sites in 5 provinces (only those providing ARV services to children) were included in the study
- Semi-structured interviews with 72 HCWs (Facility Managers; doctors, nurses, pharmacists, counsellors, social workers)
- Structured questionnaires administered with caregivers of children on ARVs (n=126)
- Initially we were targeting children less than 6 years but this was flexible

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Framework For Analysis To Services

SUPPLY SIDE

Public Health Facilities

- **Service Providers**
- **Infrastructure**

Private Health Facilities

- **Service Providers**
- **Infrastructure**

NGO Facilities

- **Service Providers**
- **Infrastructure**

DEMAND SIDE

Community

- **HH (Caregivers)**
- **Social Capital (Organisations)**

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Caregivers

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Caring for Children

- During the week children live with biological mother (37%), both biological parents (23%), grandmother (15%), aunt (8%), the rest with grandfather, uncle, children's home and foster parents
- During the day, largest % of children are looked after at crèche (48%) or by grandmother (14%)
- 75 % of other family member HIV+, just over half of that group on ARVs
- Mother and grandma carry the responsibility for taking child to clinic

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The Burden of Cost

- Caregivers depended on disability grant (71%), child care grants (56%), old age pension (19%)
- 17% of caregivers missed appointment because they did not have money for transport
- Cost of travel for 20 % of caregivers was over 20 Rands

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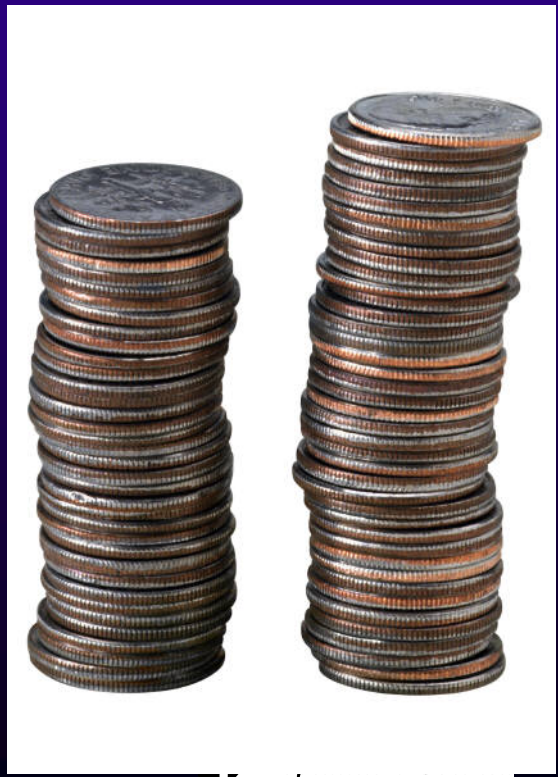
The Burden of Support for the Child?

Parents = 66% (77%,mothers)
Grandparents = 22%
Uncle = 3%
Aunt = 4%
Foster parents = 3%
Other =2%



Why Was the Child Test for HIV ?

- Chronic illness (diarrhea etc) 44%
- Hospitalization 40%
- TB 6%
- PMTCT 5%
- VCT 1%
- Other 4%

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Where Referred From Before Attending HIV Clinic

- Community Clinic = 71%
- Hospital in-patient = 21%
- Private doctor = 6%
- PMTCT = 2%

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The Pharmacist

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Major challenges:Pharmacists

- **Maintaining Stock Levels**
  - "..[pharmacy assistant] keep records…to help him see that now he has to order more because the numbers keep on going up on a daily basis. The minimum stock level won't be the same this month because the numbers are escalating."[id:40]
  - "…at this stage we don't have a clue how many children come, some weeks you get 10 and the next none, so I don't know how to order the amount of stock."[id:7]
- **Restricted Drug Options for Paediatrics**
  - "- large paediatric dosage volumes
  - "…while adults are given only 3 capsules, children are issued large volumes of medicine, tasting bad."[id:50]
- **Adherence Monitoring**
  - ""…you actually have no way of telling and seeing if the mom is taking the exact quantity or giving the child the exact quantity." [id:31]

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Major challenges:Pharmacists

- **Counseling and Stigma**
- **“Having ‘counseling facilities available in the pharmacy does not necessarily solve the problem:**

  “Other patients want to know why ‘these’ patients are going in”.[id:31]

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Major Challenges: Pharmacists

- **Storage space**
  - "paediatric ARVs are very bulky and requires much more storage space in the pharmacy."[id:15]
- **Patient load**
  - "here the mornings tend to be quieter in the pharmacy…suddenly there'll be 20-30 folders and you've got 2 hours or so to deal them them – so you don't have time to think, let alone go sit them down in the room and counsel."
- **Socio-economic circumstances of patients**
  - "…getting the mothers to come back on their repeat days…it's expensive…two weeks late- the medicines have run out…"[id:31]
  - "you don't know if the mother or the grandmother is giving the child the correct medication so it's not that direct as with an adult."[id:7]

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The Service Providers: Doctors, Nurse & Counsellors

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Main Challenges

- Lack of community awareness about services
- Stigma – staff attitude, general public
- Language and cultural barriers
- Ignorance of HIV status
- Late diagnosis
- Long diagnostic and initiation process
- Caregivers are sick parents & grannies
- Travel distances

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Main Challenges

- Staff shortages
- Staff preferences

  "working with children – it's not everybody's cup of tea, you need to be dedicated and love children – here they don't like to do children."[id:69]

- Weak PMTCT follow-up

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Entry Point to Service Delivery Need to Be Expanded

- ***PMTCT***

  "If things are running very well, the PMTCT programme would have been the perfect point to refer the kids to us, but ja, it's not really running properly…"[id:16]

- ***Primary care clinics***

  "…get the primary health care nurses to refer PCR positive infants before they're clinically unwell…"[ID:11]

- ***VCT services***

  "…staff at the day hospital currently provide VCT services to adults and refer those testing positive to the HIV clinic. They could include the testing of children that come through their services in their VCT service and likewise refer those testing positive and who may have fallen through the cracks in the system." [id:16]

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Referrals to ART From

- **Majority In-patient wards at hospitals**

"A lot from the hospital, either from the wards or from other outpatient clinics…"

"…we don't get referred that many well children…"

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Observed Models of Care

- The paediatric HIV and ARV services are ‘doctor driven’ especially for children younger than 6 yrs of age
- The minimum team composition consisted of a paediatrician, nurse and pharmacist
- The maximum team composition consisted of doctors, paediatricians, a clinical nurse, a nursing assistant, a phlebotomy nurse, a pharmacist, a pharmacists’ assistant, counsellors, a social worker and a dietician
- In some sites ‘children-friendly’ environments created and separate adolescent clinics started

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Summary of Findings

Entry Points

- **The system is reactive rather than proactive in getting children in**
- **Limitations at the community level & need for expansion (e.g., CBOs, women's groups)**
- **Greater IEC at the community level**
- **Expansion at health facilities (VCT, PMTCT, TB services, in-patient hospital settings)**

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Summary of Findings

- Problems with supply of children's drugs but this can be changed
- Suggested access to ARV services at the family level to reduce costs

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Horizons
Refining the response to HIV/AIDS through global operations research

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